



European Network of Rare Disease Help Lines members list and contact information

Organisation	E mail address	Telephone number	Other contact	More information
Spain - SIO Feder	sio@enfermedades-raras.org	918221725		
Portugal – Linha Rara	info@rarissimas.pt	300505700		
Bulgaria - Information Centre for Rare Diseases and Orphan Drugs (ICRDOD)			https://www.raredis.org/?page_id=1375&lang=en	
Italy - Università di Padova, Coordinating Centre for Rare Diseases, Veneto Region	malattierare@pediatria.unipd.it	00 39 049 82 15 700		http://malattierare.regione.veneto.it/
Romania - Romanian Myasthenia Gravis National Information Centre	asociatia.miastenia@gmail.com	0744704399	http://miastenie.ro/contact/	www.miastenie.ro http://miastenie.ro/helpline-info-mg-ro/
Romania - Romanian National Alliance for Rare Disease (NORO Help Line)	office@apwromania.ro	0040-260.611214		
Italy – Telefono Verde Malattie Rare		800896949		http://www.iss.it/index.php?lang=1&id=109&tipo=35



Croatia – Croatian Help Line for Rare Diseases	rijetke.bolesti@gmail.com	00385 1 2441 393	https://hr-hr.facebook.com/HrvatskiSav ezZaRijetkeBolesti	http://www.rijetke-bolesti.hr/rare-diseases-croatia/#Who-we-are
France - Maladies Rares Info Services (MRIS)	info-services@maladiesrares.org	0156538136	http://www.maladiesraresinfo.org/ecoute/par-e-mail.html	
Switzerland (Infos Maladies Rares)	contact@infomaladiesrares.ch	0848314372	http://www.info-maladies-rares.ch/nous-contacter/	http://www.info-maladies-rares.ch/
Ireland - National Rare Diseases Office (NRDO)	rare.diseases@mater.ie	018097475		https://www.hse.ie/eng/services/list/5/rarediseases/
Hungary – Lifebelt	mentoov@rirosz.hu	0617904533		http://mentoov.rirosz.hu http://mentoov.rirosz.hu/all-project-list/kikvagyunk/
Denmark – Rare Disorders Denmark	sjn@sjaldnediagnoser.dk	33 14 00 10		www.sjaldnediagnoser.dk/helpline
AFM Telethon	accueifamilles@afm.genethon.fr	0800353637		https://www.afm-telethon.fr/services-aux-familles-malades
NORBS (Serbia)	office@norbs.rs	0800333103	www.norbs.rs	
Seltene Krankheiten (Schweiz)	selten@kispi.uzh.ch	044 266 35 35		www.kispi.uzh.ch/helpline-selten